Call to action: improving the lives of people with hidradenitis suppurativa (HS)

February 2024

This report was developed as part of a project which is led by The Health Policy Partnership (HPP) with guidance from a multidisciplinary Steering Committee. HPP was commissioned by UCB, which initiated and is funding the project. UCB reviews all outputs, but editorial control lies with the members of the project's Steering Committee. Contributing experts are not paid for their time.

The Health Policy Partnership

Funding disclaimer

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About this report

Research, coordination and drafting were led by Chris Melson, Jody Tate, Oriana Carswell and Elena Conroy of HPP. HPP is grateful to the members of the project's Steering Committee who, as co-authors, closely guided the development of the document and volunteered their time to be interviewed and to review the report.

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- **Mona Ghassemi**, Germany
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This international report was developed based on literature review and a limited set of interviews with people living with HS and healthcare professionals. The research focused largely on ten countries: Canada, Denmark, France, Germany, Italy, Japan, the Netherlands, Spain, Sweden and the United Kingdom. Further insights were drawn from a limited literature review of 12 additional countries: Australia, Brazil, Greece, Israel, Mexico, Poland, Romania, Saudi Arabia, South Korea, Taiwan, Turkey and the United Arab Emirates.

We would also like to thank the following organisations for their endorsement:

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Foreword

Hidradenitis suppurativa (HS) is a condition few people have heard of, but it is not uncommon. In fact, this painful, inflammatory skin condition affects around 1 in 100 people across the world, yet awareness – even among healthcare professionals – is worryingly low. As a result, people living with HS wait an average of 10 years to receive an accurate diagnosis, during which they may face many years of worry, uncertainty and symptoms that can become even more severe.

The impact of HS on people's lives cannot be underestimated. It is a very complex condition that can be accompanied by intense pain, unpleasant smell and scarring. Many people living with HS face a significant impact on their ability to work, socialise, have relationships and even undertake day-to-day activities. They may also be affected by anxiety or depression. As such, it is essential that people living with HS can easily access comprehensive, multidisciplinary and tailored care, which can address both physical and mental symptoms. But for most people living with HS, this is not the reality, and many face unacceptable challenges and barriers in accessing the full range of care they need.

This international report has been developed in close consultation with people living with HS, with the aim of communicating the condition's extensive impact. It highlights the most important policy and system barriers that policymakers across the world must urgently address. We believe that, if implemented, the recommendations in this report will ultimately improve the lives of people living with HS.

We encourage all patient associations, clinical societies, policymakers and any other interested parties to use this report to advocate for change. By working together, we can ensure that everyone living with HS receives the care, treatment and support they need and that future generations of people with HS do not face the same challenges that are sadly so common today.

Please join us in sharing this report and using it to drive change.

The Project Steering Committee

Executive summary

Executive summary

Hidradenitis suppurativa (HS) is a chronic skin condition that can be extremely painful. Affecting around 1 in 100 people,[1] HS is an inflammatory condition characterised by recurrent flare-ups of painful nodules, which can become abscesses that look like lumps or boils,[2 3] and the formation of draining tunnels under the skin.[4] These abscesses may rupture, resulting in a discharge that can have an unpleasant smell and stain clothing, and can cause scarring on the body.[5 6] HS affects three times as many women as men in Western countries, but this trend is reversed in East Asia, where prevalence is over twice as high among men as among women.[7-11]

HS can have a significant and detrimental impact on people's lives. Pain is a major and debilitating symptom experienced by almost all people living with HS.[12] HS symptoms can affect people's ability to carry out daily activities such as going to work.[13 14] In addition, scarring and the unpleasant smell can make people feel embarrassed and self-conscious, leading to issues related to social life and personal relationships.[15] People may also face financial costs associated with managing the condition.[16] The sprawling impact on every aspect of people's lives contributes to the condition being highly distressing and affecting mental wellbeing.[17]

Management of HS can be complex, requiring a combination of treatments and specialists. People living with HS can have a range of needs that may require care from an array of healthcare professionals including dermatologists, surgeons, mental health professionals, wound care nurses[18 19] and pain management specialists.[20] Effective treatment options are currently limited[7] and will often involve a combination of medical and surgical interventions.[21]

A number of policy and system barriers are preventing people from accessing the best possible care. Awareness of HS is low among both healthcare professionals and the general population, leading to an average delay of 10 years before someone receives an accurate diagnosis.[18] The lack of uniformly effective treatment options and inequitable access to multidisciplinary care is contributing to the condition being unevenly managed, leading to high rates of treatment dissatisfaction and reliance on costly and often inadequate emergency care.[22 23] Furthermore, the long-term use of antibiotics, which is currently considered a key part of HS treatment, may be contributing to the global threat of antimicrobial resistance[24] and thus risking the effectiveness of future treatments for all infections.[25]

These ten priority recommendations have been developed by the authors of this report and, if implemented, they would address these barriers and ultimately improve the lives of people living with HS.

Policymakers and decision-makers must urgently take the following actions:

1. **Plan, deliver and support patient-driven campaigns through social media, healthcare settings and patient organisations to raise public awareness of HS**, to mitigate stigma and encourage people living with HS to seek care
2. **Raise awareness around the signs and symptoms of HS among healthcare professionals** to improve referral rates and speed of diagnosis. This should target primary care physicians, dermatologists, emergency care clinicians, gynaecologists, school nurses, sexual health clinicians, mental health professionals and paediatricians.
3. **Ensure all clinical guidelines and care pathways incorporate formal shared decision-making processes to empower people living with HS to have more say around the treatments that are most appropriate for them**, including innovative treatments, based on the latest evidence and personal preferences.
4. **Ensure sustainable and equitable access to the most effective treatments for HS**, both now and in the future.
5. **Introduce a treatment guide for people living with HS that provides clear information, including on side effects and safe self-treatment of HS symptoms**, to ensure people are informed and supported in making decisions over their own treatment and care.
6. **Ensure centres delivering HS care have established antibiotic stewardship programmes that include guidance to healthcare professionals on choosing the correct antibiotics and monitoring their effectiveness**, to encourage appropriate use of antibiotics and mitigate the risk of antimicrobial resistance.
7. **Improve quality of and access to HS emergency care** by delivering education programmes to healthcare professionals, including management in emergency care, as part of future updates to clinical guidelines, and by ringfencing some emergency dermatology appointments to guarantee access to urgent dermatological care.
8. **Develop pathways that encourage multidisciplinary care** involving dermatologists, surgeons, pain management specialists, wound care nurses and specialist mental health support, as well as care for common conditions that are associated with HS. This care should be either delivered within one centre or coordinated and easily accessible for people living with HS, and should leverage the use of secure online or telephone services where appropriate.
9. **Expand government support for people struggling with HS-related employment challenges and costs**, such as treatment and wound care.
10. **Raise awareness of HS among employers** and encourage workplaces to invest in reasonable work adjustments and flexible working arrangements to accommodate the needs of people living with HS.

What is hidradenitis suppurativa?

What is hidradenitis suppurativa?

Hidradenitis suppurativa (HS) is a long-term and painful skin condition that can be debilitating. HS, also known as acne inversa, can cause significant physical challenges and lead to severe psychological distress for some people.[5 21 26] It is an autoinflammatory condition that contributes to inflammation below the surface of the skin.[27 28] It often starts in a person's late teenage years and is characterised by recurrent flare-ups of painful nodules, which can become abscesses that look like lumps or boils,[2 3 29] and the formation of draining tunnels under the skin.[4] These abscesses can rupture, resulting in a discharge that may have an unpleasant smell and stain clothing, and can cause scarring on the body, all of which can lead people to feel embarrassed or ashamed.[5 6 30] The draining tunnels associated with HS can connect between nodules and/or abscesses, producing blood and discharge.[4] These nodules, abscesses and tunnels are typically located in areas of the body that are subject to skin-on-skin friction, such as the armpit, groin, genitals and buttocks, but can occur in other parts of the body too.[4 21 26 31 32] In some cases, people may have HS as part of a range of syndromes that involves immune-related conditions such as arthritis and acne, which can further complicate the management of HS.[33] HS is a progressive condition[34] but early diagnosis and treatment may reduce the risk of the condition reaching a severe stage and potentially leading to irreversible damage to the skin and scarring.[8 35-37]

HS is surprisingly common, being thought to affect around 1 in 100 people across the world, although this is likely an underestimation. Estimates of HS prevalence vary between countries, ranging from approximately 0.04% to 3.8% of the population,[38 39] but global prevalence is believed to be 1%.[1] The exact prevalence of HS may be difficult to determine because it is often misdiagnosed as conditions such as ingrown hair, folliculitis or acne, so it is likely underdiagnosed.[40]

Women are disproportionately affected by HS in Western countries, but this trend is reversed in East Asia. In Western countries such as Denmark and the Netherlands, the condition affects three times as many women as men;[7 8] however, in Japan, South Korea and Taiwan it is two to three times more common among men than women.[9-11] The exact reasons for this difference are not known but may include differences in genetics, smoking rates and health-seeking behaviours.[41 42]

The needs of people living with HS can be complex and require care from a range of specialists. Dermatologists play a central role in the management of HS, but the complex needs of people living with the condition mean they require care from a variety of healthcare professionals.[18 31] Treatment for HS can involve a combination of medication and surgery.[21 43] In addition, HS is associated with people having a range of other conditions such as depression, anxiety, diabetes, inflammatory bowel disease and axial spondyloarthritis (painful chronic arthritis that mainly affects joints in the spine),[44] meaning that HS often requires multidisciplinary care.[9 17 31 45 46]

Unevenly managed HS can result in considerable societal costs through the loss of productivity and the frequent use of high-cost services. HS often affects people during their most productive years, which means people living with HS are more likely than the general population to miss days of work, be impaired at work and be unemployed.[47-49] Additionally, high-cost care settings, such as the emergency department and inpatient care for surgery, are used more frequently by people living with HS.[23 50] This combination of factors means that HS can lead to significant costs to economic and health systems. In Spain, for example, the cost of treating HS has been estimated to exceed €1 billion per year.[16] In Germany, the estimated cost of HS-related loss of productivity alone is approximately €12.6 billion per year.[47]

How does HS impact people's lives?

How does HS impact people's lives?

HS has one of the highest impacts on quality of life among all dermatological diseases. It can affect almost every part of a person's life, including their personal relationships, work and social life; this ultimately contributes to the condition being highly distressing and affecting mental wellbeing.[3 47 51]

Pain has a major effect on people's lives

Pain is very common for people living with HS and drives many of the challenges related to the condition. Experienced by almost all people living with HS, pain is a major and debilitating symptom which has been described as relentless, extreme and sometimes unbearable.[3 12 52 53] The high intensity and frequency of pain is a persistent burden and has a huge impact on the quality of life of people living with HS.[52 54]

Mental health issues are common among people living with HS

HS has a significant impact on mental health, with many of the people affected experiencing depression and anxiety as a result of their physical symptoms. HS symptoms such as pain, scarring and the smell associated with the discharge can have a significant impact on people's mental health.[15 17] An international systematic review that included data from 40,307 participants found that almost 17% of people living with HS have experienced depression (compared with 5% among the global adult population).[55 56] These numbers were even higher in Canada, Germany, Mexico, Poland and Turkey, where studies have found depression to be experienced by approximately 39–54% of people living with HS.[14 57-60]

People living with HS may be at a greater risk of suicide due to the distressing nature of their condition. In some cases, the mental health of people living with HS can deteriorate to the extent where they may consider suicide.[3 61] A study in Denmark found people living with HS to be twice as likely to die by suicide as people without HS.[62]

The unpredictability of HS can make people feel like they have lost control of their lives. It is difficult to predict when a flare-up of HS is going to occur.[63] The lack of control over when symptoms may appear can have a significant emotional impact.[15] One person interviewed for this report said they felt their HS was controlling their life.[64]

Annette's story

Annette, who is from Sweden, had her first symptoms when she was 16. She lived in various countries throughout her life before eventually receiving a diagnosis in Slovenia, 19 years later. In recent years, Annette's condition has deteriorated, causing her pain and making her feel more tired – sometimes preventing her from going out to meet friends. Living with this chronic pain has had a significant impact on her mental health.

'My mental health has been worse in the past 10 years because I've had more frequent flare-ups. I also have spondylitis in my back, which makes it harder for me to move. It's difficult to always live with chronic pain. When I was a student, I got this tension headache. And the first time I had it, I was just lying down with a wet towel over my face crying because it was so painful. But I had to learn to live with it.'

HS can also have an emotional impact on the person's loved ones and carers. Feelings of worry, frustration and exhaustion are common among families, loved ones or carers of people living with HS.[65] In a 2020 Polish study, it was found that almost two thirds of partners of people living with HS reported that the condition contributed to their experiencing emotional distress.[65]

Social life can be negatively affected by HS symptoms

The shame experienced by people living with HS can cause them to withdraw from social situations and become isolated, further impacting their mental wellbeing. People living with HS can feel embarrassed and self-conscious because of their symptoms.[15,66] A study in Australia found that around four in five people living with HS had felt embarrassed by their scars and abscesses in the past six months.[67] A person with HS interviewed for this report disclosed that not knowing other people living with HS made them feel even more isolated.[68]

> **My social life dwindled completely. I shut everybody out and lost a lot of friends. I didn't want to go anywhere or do anything. I just felt like I wasn't fun to be around so pushed everybody away.**
>
> CHEVONNE SMELLIE, HIDRADENITIS AND ME, CANADA

HS symptoms can cause self-consciousness, leading some people to avoid social situations. Abscesses may rupture and draining tunnels may leak, potentially leading to an unpleasant smell or clothes being stained.[6,18] Not knowing when this might happen can make people avoid social situations entirely.[69] One person living with HS interviewed for this report revealed they used to sew sanitary towels into their shorts to mitigate the risk of a flare-up leaking.[70] Another individual said they have to avoid wearing certain clothes in case their abscesses or tunnels start leaking.[68]

Pain and fatigue can prevent people from being able to take part in social activities, further contributing to feelings of isolation. Pain and fatigue are very common HS symptoms and can have a huge impact on people's ability to take part in social activities.[18,71] Some of the people interviewed for this report who are living with HS said pain restricts them from being able to participate in activities like sports and dance.[72,73] One person noted that they can sometimes feel too tired to socialise, making them feel more isolated.[72]

Angela's story

Angela, who is from the UK, had her first symptoms when she was only 10 years old. She told no one at the time and dealt with it herself. With no information about HS, Angela thought her symptoms might have been cancer until her eventual diagnosis 11 years later. This had a huge and sustained impact on her mental health for most of her childhood.

'As a child, I didn't talk to anyone about it. I just used toilet paper wedged in my clothes. I'd had migraines from quite an early age and they worsened. But I used that as part of my cover story when I wasn't able to do things. I just assumed that lumps under the skin would be cancer and that it would kill me. I lived with that for 11 years, thinking that I would die. And I think some days, I would rather have died. And I was disappointed that it hadn't killed me yet. It had such a significant effect on my mental health – I was a depressed child.'

The social life of loved ones or carers may also be affected by HS. The impact of HS on the person's social life may have a knock-on effect on partners or carers.[65 74] These people may need to change plans or adjust daily activities to accommodate HS flare-ups, or may feel guilty for socialising if the person with HS cannot.[65 74]

People living with HS often experience challenges around intimacy

Pain can make it difficult for people living with HS to be intimate, which can significantly impact their quality of life. A survey of people living with HS in Canada found that around nine in ten people reported a negative impact on intimacy,[71] while people living with HS interviewed for this report revealed that the intensity of pain and location of symptoms can make intimate physical contact difficult.[70 73] Intimacy is an important part of life and the challenges faced by people living with HS in this regard have a huge effect on their quality of life.[75]

People living with HS may feel self-conscious about their bodies, leading to distress around intimacy and concerns around finding a partner. HS can make people feel negatively about their bodies, reducing self-confidence.[76 77] Many people report concerns that their HS will affect their chances of having a relationship.[78]

Women living with HS may encounter unique challenges related to pregnancy and breastfeeding. The role of hormones in HS is not yet fully understood;[79] however, the link between pregnancy and HS disease course[80] suggests some association. Pregnancy can have a variable impact on women's HS symptoms; approximately a quarter of women experience symptom improvement during pregnancy, while around one in five women experience symptoms worsening.[80] In addition, one systematic review found that more than half of women living with HS experienced a flare-up after childbirth.[80] While HS symptoms located on the breast do not usually affect a baby's ability to feed,[81] they may lead to discomfort for the woman.

People living with HS may be at greater risk of intimate partner violence. A study in Canada found that having HS can increase the likelihood of being subjected to violence by a partner when compared with the same risk for people with acne.[82] Although the reasons for this are not clear, it is in line with other studies that indicate women with a disability are at higher risk of experiencing partner violence than women without a disability.[83]

Silvia's story

Silvia, from Spain, had her first symptoms when she was 13. As her HS became more severe, she became less able to move and was eventually unable to leave the house. This led to her losing friends, stopping work and ultimately becoming extremely isolated.

'When I had to stop going out because I couldn't move, my friends disappeared. I didn't have any friends anymore. They didn't care that I couldn't go out or that I couldn't move. They simply stopped being around. Socially, if you're not visible, if people don't know what your condition is, people aren't going to understand it. And if they don't understand it, they end up leaving you to one side and you end up being alone.'

Working and studying can be difficult for people living with HS

HS symptoms can lead to people struggling with their studies, missing work or working when they are not well enough. Symptoms of HS can force people to take many days or even months off work.[14] People interviewed for this report said flare-ups, pain and surgical treatments led to work absences.[64 70] One study in Germany found that employees living with HS took 32.5 sick days per year vs. the average German employee who missed 10.6–10.8 days per year.[47] On the other hand, people may still go to work despite being impaired by their symptoms.[47 48] Some of the interviewees living with HS said they experienced interruptions to their studies as a result of their symptoms, which flared up during periods of high stress, for instance, while preparing for and taking exams.[68 84]

> **"I missed a lot of days at school; I looked back at school reports and there was barely a term where I'd done a full week."**
>
> ANGELA GIBBONS, PATIENT REPRESENTATIVE, UK

HS can lead to people losing their jobs or prevent them from ever being able to work. Unemployment is between two and six times higher among people living with HS than the general population.[47 48] One person living with HS interviewed for this report commented that their symptoms have meant they have never been able to find employment that works for them.[85] For others, taking numerous sick days owing to their symptoms or treatment has resulted in them losing their job or being pressured to quit.[64 73]

Challenges around work can have a significant impact on the mental health of people living with HS. Being able to work can be an important part of an individual's sense of self-worth. When HS restricts people's ability to work, this can have a significant negative impact on how they feel about themselves and can exacerbate their mental health issues, according to some people living with HS who were interviewed for this report.[73 85] Those interviewees whose ability to work is affected by their HS have expressed their desire to continue to work.[70 73 85]

Bente's story

Bente, who is from Denmark, first found abscesses on her body as a teenager. They were painful and located in areas of her body that would make it difficult to do the things she loved, like cycling. She would wear long skirts instead of jeans because she was in pain. As she grew older and her HS worsened, the pain meant Bente struggled with intimacy and this had a serious impact on her quality of life.

'It was really hard to manage on an everyday basis. Sometimes I could hardly sit and I loved to ride my bicycle – and [the abscesses] were placed exactly where I had to sit. When my HS was at its worst, I had to talk to my husband about where he can touch me and how much he can touch me. I often refused sex because it was too bad. It was just so painful.'

Managing HS can result in personal financial costs

People living with HS may face a range of out-of-pocket costs for treatment and wound care. HS is a complex condition that requires a combination of medical treatment and long-term wound care.[21 31 86] In some cases, depending on a particular health system or medical insurance provider, people may have to pay for certain medical treatments.[71] People living with HS interviewed for this report said they regularly have to bear expenses for wound care supplies such as bandages, tape, creams and antiseptics.[64 84 87] In Spain, these personal costs amount to an average of over €500 a year.[16] Wound care is a daily part of managing HS, with one in six people needing five or more changes to their dressing a day, according to an international study (including people from Australia, Canada, Denmark, Sweden, the UK and the US, among others).[88] Tending to HS dressings can take over 30 minutes a day, potentially impacting people's ability to work.[88] Almost half of people report HS-related wound care affecting their financial wellbeing.[88]

Many people living with HS also struggle with non-medical costs. These may include travelling to medical appointments, buying extra clothing and having higher utility bills as a consequence of taking more showers and frequent washing of bedding and clothing, according to people interviewed for this report.[84 85] One person had spent significant amounts of money travelling abroad to receive a treatment which had been effective for them but was not available in their home country.[85]

HS-related work issues can lead to additional financial strain. The impact of HS on someone's ability to work can lead to a reduction in or total loss of their income, which can cause further financial difficulty, according to people interviewed for this report.[73 87]

The loved ones or carers of people living with HS also feel the financial impact of the condition. For partners of people living with HS, the most commonly reported impact on quality of life was the increase in expenditure driven by the condition, according to a study in Poland.[65] If someone living with HS is unable to work, they may be reliant on their loved ones or carers to financially support them and help them pay for HS-related costs.[74] This may be a significant source of distress for loved ones.

Marie-France's story

Marie-France is from France and has had HS from a young age. Although it was painful, she never wanted her symptoms to prevent her from doing the things she wanted to do, like dancing or paragliding, even if she suffered through the pain. The hardest point for her was when she lost her job; her HS had forced her to take too many sick days and she was deemed to not be fit for work. This had a serious effect on Marie-France's mental health and led to her needing psychological support and treatment.

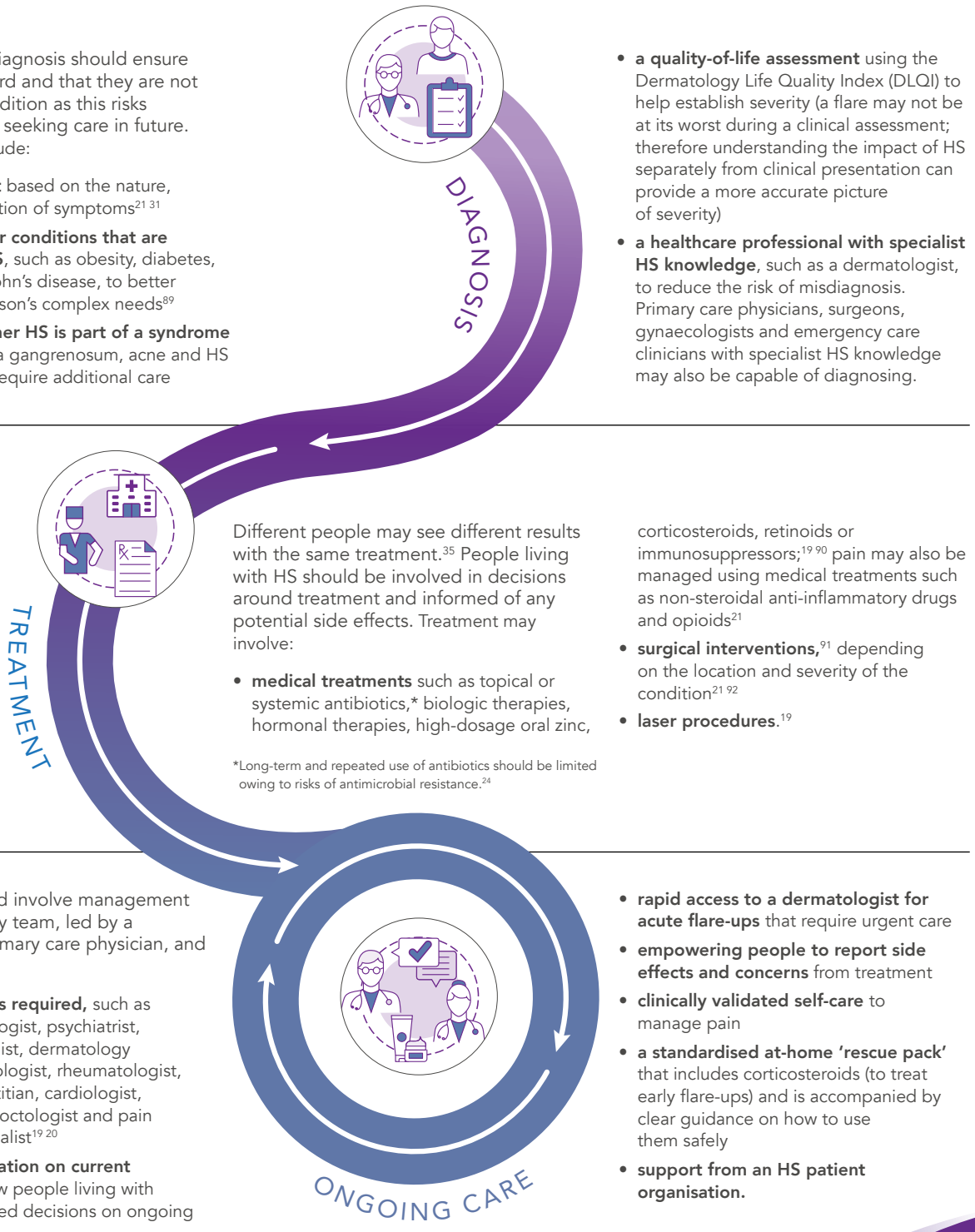
'In France, when you are out of work for more than eight days, you have to go to a physician who must confirm you are fit to work but I was deemed to be "medically incapacitated" without being told. I asked my work if I could work from home but they said no. When you're sick and you have no work – that's a really depressing situation. I loved my work; it was really hard when I lost it.'

What does best-practice care for HS look like?

What does best-practice care for HS look like?

HS can be a frustrating condition to manage, both for people living with the condition and for the healthcare professionals treating it. While there is currently no cure for HS, its impact can be reduced if people receive best-practice care at every stage (*Figure 1*). This best-practice care HS pathway has been developed by the authors of this report.

Figure 1. Best-practice HS patient pathway



The process of HS diagnosis should ensure the person feels heard and that they are not blamed for their condition as this risks deterring them from seeking care in future. Diagnosis should include:

- **clinical assessment** based on the nature, frequency and location of symptoms[21 31]
- **screening for other conditions that are associated with HS**, such as obesity, diabetes, depression and Crohn's disease, to better understand the person's complex needs[89]
- **establishing whether HS is part of a syndrome** – such as pyoderma gangrenosum, acne and HS (PASH) – that may require additional care
- **a quality-of-life assessment** using the Dermatology Life Quality Index (DLQI) to help establish severity (a flare may not be at its worst during a clinical assessment; therefore understanding the impact of HS separately from clinical presentation can provide a more accurate picture of severity)
- **a healthcare professional with specialist HS knowledge**, such as a dermatologist, to reduce the risk of misdiagnosis. Primary care physicians, surgeons, gynaecologists and emergency care clinicians with specialist HS knowledge may also be capable of diagnosing.

Different people may see different results with the same treatment.[35] People living with HS should be involved in decisions around treatment and informed of any potential side effects. Treatment may involve:

- **medical treatments** such as topical or systemic antibiotics,* biologic therapies, hormonal therapies, high-dosage oral zinc, corticosteroids, retinoids or immunosuppressors;[19 90] pain may also be managed using medical treatments such as non-steroidal anti-inflammatory drugs and opioids[21]
- **surgical interventions,**[91] depending on the location and severity of the condition[21 92]
- **laser procedures**.[19]

*Long-term and repeated use of antibiotics should be limited owing to risks of antimicrobial resistance.[24]

Ongoing care should involve management by a multidisciplinary team, led by a dermatologist or primary care physician, and should include:

- **other specialists as required,** such as a surgeon, psychologist, psychiatrist, wound care specialist, dermatology nurse, gastroenterologist, rheumatologist, gynaecologist, dietitian, cardiologist, endocrinologist, proctologist and pain management specialist[19 20]
- **up-to-date information on current treatments** to allow people living with HS to make informed decisions on ongoing treatment
- **rapid access to a dermatologist for acute flare-ups** that require urgent care
- **empowering people to report side effects and concerns** from treatment
- **clinically validated self-care** to manage pain
- **a standardised at-home 'rescue pack'** that includes corticosteroids (to treat early flare-ups) and is accompanied by clear guidance on how to use them safely
- **support from an HS patient organisation.**

What are the policy and system barriers to best-practice care?

What are the policy and system barriers to best-practice care?

A series of barriers are preventing people living with HS from receiving the best possible care. Many people may not be receiving the care they need as a consequence of a lack of disease awareness,[18] issues around treatment provision,[7] inequitable availability of multidisciplinary care[71 93] and antimicrobial resistance.[24] In addition, people living with HS who were interviewed for this report said they received insufficient government support.[73 87] Some of the differences between countries that may affect the care and support people in these countries receive are outlined in the *Appendix*.

Embarrassment, stigma and fear can mean some people avoid seeking medical attention and their symptoms become worse

People living with HS can feel too embarrassed about their symptoms to seek medical care. People may be scared to talk to others about their HS over fears it may be perceived as contagious or a sexually transmitted disease.[94] People living with HS may also fear other people's reactions to revealing things such as scarring or unpleasant smell.[15] This may contribute to people with HS not talking about their condition with loved ones or with a clinician, potentially leading to disease progression.[15 32] In Saudi Arabia, for example, almost a quarter of young women living with HS said they had no intention to seek medical treatment for their symptoms,[95] potentially driven by their fear of stigma.

Chevonne's story

Chevonne, from Canada, was 15 when she first had symptoms. She did not tell anyone about them for a long time, but when the pain became unbearable she eventually went to the emergency department. This started a period where Chevonne would use walk-in clinics and emergency care as her main source of healthcare for her HS. During this time she experienced highly distressing interactions with doctors who lacked understanding of HS and basic compassion about her condition. This made Chevonne avoid seeking care until she was desperate.

'In my experience, they've made me feel dirty, or that I'm wasting their time. I had a nurse actually yelled at by her supervisor for spending too much time on my wounds. They told me to make sure I take a shower before I come in, which wasn't easy for me because I had just finished work and would go straight there. I've had a doctor tell me I smell – it would just cause me not to even want to go to the doctor or seek help. So there are long periods where I wouldn't go until I was desperate. They can just be so mean.'

A lack of understanding and sensitivity around HS can lead to distressing healthcare experiences for some people. In their search for a diagnosis, people living with HS interviewed for this report have encountered healthcare professionals who have a limited understanding of HS, resulting in insensitive and unnecessary questions around hygiene, weight loss and sexual activity.[64 70 84] This left these people feeling ashamed, embarrassed and distressed.[64 84] In Turkey, HS is often referred to as 'dog nipple disease', including by healthcare professionals, further adding to the stigma; 80% of people in one study reported that this term made them feel stigmatised.[96]

Reluctance to seek medical advice for early symptoms may further delay diagnosis and access to treatment, exacerbating the severity of HS. People interviewed for this report had poor experiences of healthcare which discouraged them from seeking medical attention in the future, contributing to longer delays in diagnosis.[64 84] Longer delays are associated with the condition becoming more severe.[40]

> **'I think the best thing is to speak – if people don't know about an illness, how can they understand it?'**
>
> MARIE-FRANCE BRU-DAPRÉS, AFRH, FRANCE

Public campaigns to raise awareness could help people living with HS and the wider community better understand the condition, encouraging people with symptoms to see their doctor and potentially reducing delays in diagnosis. Increasing awareness of HS among the public may help combat the stigma around the condition, making people more comfortable to seek medical assistance.[97] This is likely to improve the speed of diagnosis. People living with HS interviewed for this report spoke about the importance of being open about their HS to allow others with the condition to not feel isolated and to improve understanding among the general public.[70 73 85] Social media could be an effective method of raising awareness, considering the young age at which symptoms are first recognised and the high use of social media among this age group.[98]

Yuki's story

Yuki's symptoms started when he was in high school in Japan. They made him feel very self-conscious and he thought carefully about what clothes to wear to make his symptoms less visible. When abscesses opened and stained his clothes, Yuki felt dirty and uncomfortable. Before his diagnosis, he felt very isolated because he knew nothing about HS and knew no one going through what he was having to deal with.

'When the symptoms were there, I didn't know what was causing them. I thought, "How much longer do I have to continue suffering from this?" I did some searches on the internet about symptoms such as pus under arm, but couldn't see anything that led me to HS. I couldn't find any peers, either – I felt very isolated.'

Patient organisations can play a key role in disseminating information and providing a community for people living with HS to share experiences, particularly for demographics with lower digital literacy. However, these organisations are not yet active in all countries, and this may contribute not only to a lack of awareness of HS in those countries but also to people living with HS feeling more isolated – including one person interviewed for this report.[68]

RECOMMENDATION FROM THE AUTHORS

Plan, deliver and support patient-driven campaigns through social media, healthcare settings and patient organisations to raise public awareness of HS, to mitigate stigma and encourage people living with HS to seek care.

Low awareness among healthcare professionals is contributing to delays in diagnosis, during which time the condition can become more severe

Limited awareness of HS among some healthcare professionals contributes to an average delay of 10 years before people receive an accurate diagnosis. Awareness of HS among many healthcare professionals is considered low,[11 95] particularly among those that people living with HS are likely to come into regular contact with, including primary and emergency care clinicians, according to a healthcare professional interviewed for this project.[99] This contributes to HS being frequently misdiagnosed.[34] One study in Germany found that people with a late diagnosis of HS had received an average of five misdiagnoses, contributing to further delays.[40] Limited awareness among primary care clinicians may also lead to slow referral to dermatologists, who play a central role in HS diagnosis[18] – although people living with HS interviewed for this report have even experienced low awareness among dermatologists.[85 87] Globally, this results in people experiencing an average delay of just over 10 years from initial symptoms to diagnosis.[18]

Mona's story

Mona was given very little information about HS after she was diagnosed by an emergency care clinician; no one told her she needed to see a dermatologist. The healthcare professionals that she saw near her home after her diagnosis had little knowledge of HS or how to treat her. This forced Mona to look for a specialist further afield. She now receives care from a dermatologist who specialises in HS, but this person is based very far away from Mona's home.

'The doctors around me said that I needed to use some cream, but once I showed them my scars they realised it was much more serious. They knew that they needed to do more but didn't have any idea what to do. I searched online to find a specialist and found one in Berlin, which is 700km away. I have email contact with her, but mainly I see her when I think I need an operation.'

Delays in diagnosis prevent people from receiving treatment and their condition may advance during this time. Long delays in diagnosis can mean the condition becomes more severe, with a greater impact on quality of life.[67 100 101] A multinational study found that 70% of people living with HS had been diagnosed at a moderate-to-severe stage, which is less successfully managed than mild disease.[32] Progression to this stage may be prevented by timely access to treatment as a result of an earlier diagnosis.[8 38]

Delayed diagnosis may contribute to higher costs for the health system. The majority of people living with HS visited a healthcare professional more than five times before receiving a formal diagnosis,[18] while a study in Spain found that people visited an average of around 15 healthcare professionals from a range of specialties before getting a diagnosis.[16] This indicates the frequent use of healthcare resources during the pre-diagnostic period. Furthermore, delayed HS diagnosis is also associated with people having more surgical procedures, which are cost-intensive and can be complicated by infection.[23 40 43]

Educational programmes targeted at healthcare professionals may improve the speed of HS diagnosis. In order to reduce delays in diagnosis, understanding of HS is needed among healthcare professionals. This is particularly important for those who encounter people living with HS, such as dermatologists, primary care physicians and emergency care clinicians.[16 67 98] A healthcare professional interviewed for this report also suggested awareness should be raised among gynaecologists.[102] Understanding could be improved among healthcare professionals through greater representation of HS in medical education.[103]

RECOMMENDATION FROM THE AUTHORS

Raise awareness of the signs and symptoms of HS among healthcare professionals to improve referral rates and speed of diagnosis. This should target primary care physicians, dermatologists, emergency care clinicians, gynaecologists, school nurses, sexual health clinicians, mental health professionals and paediatricians.

Susanne's story

Susanne, from the Netherlands, was 13 when she first developed HS symptoms on her shoulder, an uncommon place for HS symptoms. Gradually, the inflammation spread across her back to her groin, armpit and face. She was referred to a dermatologist but was wrongly diagnosed with acne. Susanne had serious side effects from the treatment she was put on and therefore lost trust in dermatologists. Ultimately, Susanne received her HS diagnosis from another dermatologist, 19 years after her first symptoms.

'The first dermatologist I was sent to told me it wasn't HS because it was on my back, and said it was acne. They gave me treatment which made me really depressed. It dried out my skin and would make my lips bleed when I smiled. My hair was falling out; it was horrible. My parents talked me out of using the treatment and we no longer trusted the dermatologist. I only went back to a dermatologist when I was 18. I went to the "best dermatologist in Amsterdam", who also said it wasn't HS because it was on my back and tried to put me back on the same treatment that had given me those nasty side effects. She didn't treat me with a lot of respect, and I chose not to see her again. After that, I didn't see a dermatologist for a long time.'

People do not always have prompt and equitable access to the most appropriate treatment and so continue to suffer with their symptoms

No treatment options are uniformly effective for HS and many cause side effects among some people, leading to low treatment satisfaction and a need to try many treatments to find one that works. People living with HS receive a range of medical and surgical treatments, but none of these deliver sustained improvements in symptoms for everyone.[7] In addition, people interviewed reported a number of undesirable side effects from current and previous treatments, including fevers, infection, depression and issues with gut health.[22 64 70 84 85] In one global study (carried out by centres in Australia, Belgium, Canada, China, Denmark, France, Germany, Greece, Ireland, Israel, Norway, Poland, Qatar, Spain, the UK and the US), almost half of people living with HS were either dissatisfied or very dissatisfied with their current treatment, with poor effectiveness and side effects cited as the most common reasons for dissatisfaction.[22] A large national study in Greece also found that only 20% of people reported improvements in their symptoms after receiving initial treatment.[104] This means that people may have to try many different treatments, sometimes more than once, in their search for one that is effective for them, according to a person interviewed for this project.[84] The Treatment of Hidradenitis Suppurativa Evaluation Study (THESEUS) is a large, multicentre study being conducted in the UK to understand how HS treatments are currently used;[105] the results from studies like this may facilitate improvements in HS treatment decisions.

> **"I've tried anything and everything. Either you tried it or you stayed as you were. And I wasn't very well. So, I tried everything."**
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> SILVIA LOBO BENITO, ASENDHI, SPAIN

The limited involvement of people living with HS in decisions around their treatment may exacerbate dissatisfaction, as people may remain uninformed about different treatment options, risks and benefits. People living with HS interviewed for this report have felt largely excluded from decisions around the treatments they have received, with some reporting they have had no choice whatsoever in the treatment they have been provided with.[73 84 85] One interviewee living with HS in Japan was unhappy with their doctor for treating them with surgery, which left them with scarring, without having adequately discussed other treatment options with them.[68] This procedure may not have taken place if a formal shared decision-making process had been carried out, involving an informed discussion of the advantages and disadvantages of treatment, similar to the process recommended in the EuroGuiDerm Guideline on the systemic treatment of Psoriasis vulgaris.[106]

> **"I have absolutely not felt involved in treatment decisions. For a long time, I was just given treatment without explanation."**
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> MARIE-FRANCE BRU-DAPRÉS, AFRH, FRANCE

A greater focus on involving people living with HS in decisions around their treatment could improve their knowledge, satisfaction with care and feelings of empowerment. Facilitating shared decision-making by providing people with sufficient information on treatment and potential side effects, for example through the use of patient decision aids, can significantly increase patient knowledge of HS.[107] A study on shared decision-making for people with psoriasis in Italy found that people with better knowledge of the condition were more likely to be satisfied with their care.[108] This suggests that shared decision-making for other chronic dermatological conditions, such as HS, could boost satisfaction among people living with the condition. While the North American clinical management guideline for HS includes patient preference in pain management decisions,[43] most are limited in this aspect.[5 21 31 61 109]

Early use of innovative treatments may reduce the chance of HS progressing to a more severe stage. The early use of biologics may halt HS progression.[110] This may reduce the risk of excessive scarring[110] and result in reduced healthcare costs.[111]

Many people living with HS rely on managing their condition through self-treatment, which can present risks. In the absence of access to effective treatments, many people feel the need to self-treat their symptoms, primarily to manage pain.[112] A study of people living with HS in Denmark found that approximately four in five people were self-treating symptoms, with almost half of these using needles or knives to cut abscesses open.[112] Self-treatment using these techniques can be dangerous, placing people at risk of infection and even death.[113]

People living with HS may benefit from being provided with information on how to safely self-treat symptoms such as pain. People are likely to continue to self-treat symptoms if their treatment is not yielding sustained improvements in their condition. Those living with HS could benefit from receiving information from their doctor that encourages them to avoid methods that may be unsafe, and a list of techniques that could support them in managing their symptoms safely. People interviewed for this report have used ice packs or hot compresses to reduce pain.[84 85]

RECOMMENDATIONS FROM THE AUTHORS

Ensure all clinical guidelines and care pathways incorporate formal shared decision-making processes to empower people living with HS to have more say around the treatments that are most appropriate for them, including innovative treatments, based on the latest evidence and personal preferences.

Ensure sustainable and equitable access to the most effective treatments for HS, both now and in the future.

Introduce a treatment guide for people living with HS which provides clear information, including on side effects and safe self-treatment of HS symptoms, to ensure people are informed and supported in making decisions about their own treatment and care.

Long-term use of antibiotics threatens their effectiveness by increasing the risk of resistance

Treatment for HS often involves the long-term use of antibiotics, but this may be contributing to antimicrobial resistance and pharmaceuticals in the environment, which has generated concerns regarding the long-term sustainability of the treatment. Antimicrobial resistance is considered by the World Health Organization to be one of the top ten global public health threats facing humanity, with the overuse or misuse of antibiotics identified as a primary driver of this phenomenon.[114] Antibiotics are commonly used to treat HS, but it has been found that the condition is already partially resistant to many of the antibiotics used.[90] This has raised concerns around their routine use for HS treatment, as it may be contributing to the major and urgent problem of antimicrobial resistance.[24] Recent evidence also suggests that residue of antibiotics from the treatment of humans has been found in water and soil, which may be playing a role in the acceleration of antimicrobial resistance.[115]

Antimicrobial resistance can have serious implications for future HS care and wider society. Antibiotics are the most frequently used treatment for HS,[71 93] but antimicrobial resistance may threaten their long-term utility.[25] The impact of antimicrobial resistance reaches much wider than HS, leading to increases in death, disability and the overall cost of healthcare.[114] This suggests that extra caution should be given to the prescribing of antibiotics for HS.

Antibiotic stewardship programmes, supported by further research to measure the impact of antibiotics, may help clinicians involved in HS care to minimise the risk of antimicrobial resistance. Appropriate use of antibiotics may be achieved through the roll-out of antibiotic stewardship programmes in centres that are delivering HS care, according to an expert interviewed for this report.[116] These should focus on helping prescribing clinicians seek to improve outcomes for people living with HS while reducing the risk of antimicrobial resistance.[116] According to a person interviewed for this project, more research is needed to establish which antibiotics are the most effective for each person.[84] Having a better understanding of this could reduce the need for people with HS to try multiple long-term courses of antibiotics that may be ineffective for them.[84] Adopting a 'review and revise' approach alongside this, which encourages the ongoing evaluation of treatment by prescribers, is crucial to reduce the unnecessary continuation of antibiotic therapy.[117] This could reduce the risk of antimicrobial resistance and allow people to access more effective treatment faster.[117]

RECOMMENDATION FROM THE AUTHORS

Ensure centres delivering HS care have established antibiotic stewardship programmes which include guidance for healthcare professionals on choosing the correct antibiotics and monitoring their effectiveness, to encourage appropriate use of antibiotics and mitigate the risk of antimicrobial resistance.

Inadequate access to best-practice, multidisciplinary care is leading to poor management of HS

HS is a complex condition that requires multidisciplinary care, but this appears to be rarely available, placing the burden on people living with HS to coordinate parts of their own care. Guidelines in Europe, North America, Brazil and the UK recommend the management of HS through a multidisciplinary approach – including care from dermatology, surgery, wound care, pain management and psychology – acknowledging the complex physical and psychological needs of people living with the condition.[21 43 61 109] However, in some countries this is not widely available in practice.[71 93] In the UK, for example, primary care physicians reported referring only 3% of people living with HS to a specialised multidisciplinary service,[93] while in Canada, fewer than one in five people living with HS had received psychological support for their condition, suggesting a lack of availability of holistic care.[71] In the United Arab Emirates, although some centres offer multidisciplinary care, it is acknowledged that communication between different specialties is often disjointed.[118] In Italy, multidisciplinary care is available through dedicated treatment centres,[98] but the scarcity of these means that access is inequitable, according to a healthcare professional interviewed for this report.[102]

> **"We don't have multidisciplinary care. You have to go from one to another and you have to be referred across – each time you have to convince someone that "I need this". That's really difficult."**
>
> BENTE VILLUMSEN, PATIENTFORENINGEN HS DANMARK, DENMARK

Poorly managed HS contributes to people relying on emergency care, which is costly and often considered to be of a low standard in providing HS-specific care. Ineffective management of HS and suboptimal access to dermatologists may result in greater use of more costly emergency services.[18 119] Pain management, in particular, can be overlooked,[3] with one study finding that 90% of people wanted more counselling on how to manage their pain.[52] Severe pain, draining abscesses and concern over infection may lead people living with HS to seek emergency care.[120] According to people living with HS interviewed for this report, the care received through emergency services is inadequate.[70 87] In addition, the experience of emergency care can be time-intensive and distressing,[87] with one person raising concerns about a loss of privacy in an emergency setting.[84] People living with HS can feel very self-conscious about their condition and may not want their diagnosis to be inadvertently shared in a busy emergency ward.[84] The management of HS in an emergency setting is not currently included in Brazilian, Canadian, European, North American and UK clinical guidelines, which may hamper the ability of healthcare professionals in these settings to provide high-quality urgent care.[21 31 43 61 109]

> **"I've been to the emergency department more times than I can count. In the beginning, it was probably every month or two."**
>
> CHEVONNE SMELLIE, HIDRADENITIS AND ME, CANADA

Educating emergency clinicians on the appropriate treatment for HS could lead to improvements in outcomes from urgent care. It has been reported by a person interviewed for this project that emergency care clinicians who have limited knowledge of HS may choose inappropriate treatments that may be ineffective or unnecessarily invasive.[84] Improving the understanding of HS among emergency care clinicians is likely to raise the quality of urgent care for the condition. A dermatologist interviewed for this report said their centre provides people with an information card that includes details around what HS is and the most appropriate care for that person, in the event that the person has to go to the emergency department.[121] This can improve access to adequate urgent care for people living with HS.

All dermatology departments should seek to provide some emergency appointments for people living with HS. Improved access to urgent dermatological care could limit the need for people to visit an emergency department.[18] According to a dermatologist in Canada, this is already available in some centres and people are able to receive an urgent appointment within one or two days if they are having a flare-up.[121] People living with HS could benefit from receiving this service in all centres.

Centres providing care for HS should aim to guarantee access to the specialist care needed by people living with HS. Care provided should involve a multidisciplinary approach that includes access to dermatologists, surgeons, pain management specialists, wound care nurses and mental health professionals.[19 20] HS centres should also screen for common HS comorbidities, including gastrointestinal, cardiovascular and rheumatological conditions.[109] An HS expert interviewed for this report highlighted the need for virtual psychological counselling to improve access to holistic care.[121] Facilitating access to this range of services would provide material improvements to HS care for people around the world.

RECOMMENDATIONS FROM THE AUTHORS

Improve quality of and access to HS emergency care by delivering education programmes to healthcare professionals, including management in emergency care, as part of future updates to clinical guidelines, and by ringfencing some emergency dermatology appointments to guarantee access to urgent dermatological care.

Develop pathways which encourage multidisciplinary care that involves dermatologists, surgeons, pain management specialists, wound care nurses and specialist mental health support, as well as care for common conditions that are associated with HS. This care should be either delivered within one centre or coordinated and easily accessible for people living with HS and should leverage the use of secure online or telephone services where appropriate.

Government support for people living with HS who cannot work is largely insufficient, leaving some people in financial distress

People living with HS may need to rely on government support if their condition means they are not able to work, but in some countries this may not be enough to live on. Some of the people living with HS interviewed for this report have relied on government financial support and comment that this is often inadequate.[73 85 87] Disability support for people who are temporarily or permanently unemployed varies between countries and may depend on how much the person has worked in the months and years before.[122 123] According to a patient representative interviewed for this report, it may also be hard to convince authorities that someone with HS has a disability, representing an additional barrier to accessing government support.[70]

> **"What they give you is called a non-contributory pension. And it's a tiny amount."**
>
> SILVIA LOBO BENITO, ASENDHI, SPAIN

Insufficient government support can lead to significant financial distress. Employment issues can be emotionally distressing, but this can be compounded by insufficient government support that fails to provide an adequate safety net for people living with HS, who may face challenges being able to work, according to a person interviewed for this report.[73] This may result in those people becoming dependent on loved ones and carers to provide financial support.[74] For the loved ones and carers of people living with HS who are unable to work and require regular payments for treatment or wound care, this may have a significant financial impact.[74] For people without loved ones to rely on, financial issues may be particularly challenging.

People living with HS require more support from national governments to help them through financial and employment challenges. Investment in reasonable adjustments at work that are sensitive to the needs of people living with HS, such as when they need to manage symptoms during the work day, would be beneficial.[124] More flexible working arrangement policies could accommodate people needing to attend medical appointments.[124] In addition, national governments should consider expanding financial support for people living with HS, to make it easier to access sufficient disability-induced unemployment benefit and financial support for HS-related costs. This could mitigate some of the financial and employment challenges faced by people living with HS.

RECOMMENDATIONS FROM THE AUTHORS

Expand government support for people struggling with HS-related employment challenges and costs, such as treatment and wound care.

Raise awareness of HS among employers and encourage workplaces to invest in reasonable work adjustments and flexible working arrangements to accommodate the needs of people living with HS.

Call to action and recommendations

Call to action and recommendations

We call on policymakers to recognise the devastating impact of HS and act now to alleviate its burden on the people living with the condition.

HS can be an extremely painful and debilitating condition with wide-reaching impact across some of the most fundamental aspects of a person's life. Symptoms like pain, scarring and unpleasant smell can affect people's ability to socialise, work and have relationships.[15 18 47 71] This means that people living with HS often struggle with mental health issues and low quality of life.[15 17 125]

A range of policy and system barriers are preventing people living with HS from accessing the best possible care. A lack of awareness among healthcare professionals is leading to long delays in the condition being diagnosed.[11 18 32] This is exacerbated by limited understanding of HS among the general population, which can make people feel embarrassed about their condition and avoid seeking medical attention.[15 32] Once diagnosed, the treatment people receive is often inadequate[7] and rarely are they able to access the best-practice, multidisciplinary care that HS can require.[71 93] The reliance on long-term use of antibiotics may also be contributing to the wider global issue of antimicrobial resistance,[24] further limiting treatment options. In addition, for those struggling with the financial impact of HS, insufficient government support may mean they are not receiving the help they need, according to people interviewed for this report.[73 85 87]

To address these barriers, the authors of this report urge policymakers and decision-makers to take the following actions:

1. **Plan, deliver and support patient-driven campaigns through social media, healthcare settings and patient organisations to raise public awareness of HS,** to mitigate stigma and encourage people living with HS to seek care.
2. **Raise awareness around the signs and symptoms of HS among healthcare professionals** to improve referral rates and speed of diagnosis. This should target primary care physicians, dermatologists, emergency care clinicians, gynaecologists, school nurses, sexual health clinicians, mental health professionals and paediatricians.
3. **Ensure all clinical guidelines and care pathways incorporate formal shared decision-making processes to empower people living with HS to have more say around the treatments that are most appropriate for them,** including innovative treatments, based on the latest evidence and personal preferences.
4. **Ensure sustainable and equitable access to the most effective treatments for HS,** both now and in the future.
5. **Introduce a treatment guide for people living with HS that provides clear information, including on side effects and safe self-treatment of HS symptoms,** to ensure people are informed and supported in making decisions over their own treatment and care.
6. **Ensure centres delivering HS care have established antibiotic stewardship programmes that include guidance to healthcare professionals on choosing the correct antibiotics and monitoring their effectiveness,** to encourage appropriate use of antibiotics and mitigate the risk of antimicrobial resistance.
7. **Improve quality of and access to HS emergency care** by delivering education programmes to healthcare professionals, including management in emergency care, as part of future updates to clinical guidelines, and by ringfencing some emergency dermatology appointments to guarantee access to urgent dermatological care.
8. **Develop pathways that encourage multidisciplinary care** involving dermatologists, surgeons, pain management specialists, wound care nurses and specialist mental health support, as well as care for common conditions that are associated with HS. This care should be either delivered within one centre or coordinated and easily accessible for people living with HS, and should leverage the use of secure online or telephone services where appropriate.
9. **Expand government support for people struggling with HS-related employment challenges and costs,** such as treatment and wound care.
10. **Raise awareness of HS among employers** and encourage workplaces to invest in reasonable work adjustments and flexible working arrangements to accommodate the needs of people living with HS.

Appendix. International comparison of key information related to HS

Country	Is there a national clinical guideline for HS?	Is there an HS-specific patient organisation?	Are there specialist HS treatment centres?
Canada	Yes[31]	Yes[126 127]	Yes[121*]
Denmark	Yes[128]	Yes[129]	Yes[130]
France	Yes[131]	Yes[132-134]	No information found
Germany	Yes[135]	No	Yes[23]
Italy	No†	Yes[136]	Yes[98]
Japan	Yes[137‡]	No	No information found
The Netherlands	Yes[138]	Yes[139]	Yes[140]
Spain	No	Yes[141]	Yes[142]
Sweden	No	Yes[143 144]	No information found
UK	Yes[109]	No	Yes[145]

Information collected in this table is correct as of February 2024.

* These are not formally accredited.

† Although some regional and treatment-specific guidelines exist[146]

‡ These are based on European guidelines, despite the fact that evidence suggests that HS presents differently in Japan and European countries.

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